

Recommendations for Meeting the Needs of Children and Youth with Traumatic Brain Injury

prepared by

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Forward

According to the Center for Disease Control and Prevention, injury is the single largest cause of death and disability among youth in the United States. Motor vehicle crashes, falls, recreational injuries, and child abuse are among the leading causes. The age group most at risk is the 15-24 age category. Over 90% of children with a traumatic brain injury now survive because of improved medical management (Begali, 1992). Furthermore, more than 75% of the 200,000 children hospitalized annually with TBI sustain only mild brain injuries with few residual long-term problems (Farmer and Peterson, 1995).

During 1994, 1,284 Missouri children under the age of 18 (1,457 under the age of 21) were hospitalized and reported to the Missouri Department of Health by way of the Missouri Head and Spinal Cord Injury Registry as having suffered a traumatic brain injury. The majority were discharged from the hospital to home (76%). The

average length of stay was 4.75 days with one day being the minimum and 87 days the maximum. Motor vehicle crashes were the leading cause of injuries. Most (57.1%) of these children were reported as being discharged as functioning at a level of independence or reported as functioning level as unknown (11.7%). A total of 21.4% were reported as functioning at either a dependent, partially dependent or dependent on a device at the time of hospital discharge.

Traumatic brain or head injury is usually thought of in terms of a "closed" head injury or an "open" head injury. A "closed head injury" refers to damage that occurs within the skull after a blow to the head. Although the skull may stop on impact, the brain will often continue to whip back and forth against the skull from within causing damage. The second category of head injury referred to as "open head injury" is a visible assault and may be the result of a gun shot wound. A "blow" to the head does not necessarily need to take place for a brain injury to occur. For example, in a motor vehicle injury, the rapid deceleration on impact may set up a variety of forces in the cranium that can produce a significant brain injury from acceleration-deceleration effects.

The symptoms of head injury may vary greatly, depending on the extent and location of the injury. The following are three types of impairments associated with head injury. Any or all of the impairments may occur in varying degrees and there may be other symptoms than those listed below.

- Physical impairments; including speech, vision, hearing and other sensory impairments; fatigue; headaches, lack of coordination; spasticity of muscles, paralysis of one or both sides and seizure disorders. Although many survivors of head injury may appear to be recovered physically, many may still have problems with visual perception or fine motor control.
- Cognitive impairments; including memory deficits, either long or short term; and problems with concentration, attention, perception, communication, reading, writing, planning, sequencing or judgment. Learning and classroom performance can also be affected by decreased abstract reasoning, reduced initiative and distractibility.
- Psycho-Social-Behavior-Emotional impairments; including mood swings, lack of awareness, decreased ability to take the perspective of others, self-centered behavior, anxiety, depression, lowered esteem, sexual dysfunction, restlessness, lack of motivation, inability to self-monitor, difficulty with emotional control, inability to cope, agitation, excessive laughing or crying or difficulty relating to others. Personality can be altered and the person may become argumentative or become socially withdrawn and unable to interact with peers. Often a person with a head injury will insist he or she can understand completely when in actuality is totally confused.

For many children and youth with traumatic brain injuries, their needs will be challenging to meet and will require coordinated, interdisciplinary planning involving all parties: health care providers, educators, family, the child with a traumatic brain injury, and appropriate state agencies, such as vocational rehabilitation, developmental disabilities, special health care needs and Medicaid.

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Task Force on Children and Youth with TBI

Missouri Head Injury Advisory Council

Preface

Concerned about recent trends in health care to reduce hospital stays and reports to the council of nursing home placements for children, the Missouri Head Injury Advisory Council chair, Don Claycomb, Ph.D., appointed a Task Force on Children and Youth with TBI in December 1996. While not much data or outcome studies have been published nationally yet supporting these trends, articles have been published in national journals also expressing concern that children and youth are being discharged prematurely from hospitals and inappropriately placed in the community.

The Task Force expanded its initial focus to also include the array of health care, rehabilitation, education, transitional planning, and support services needed to support children and youth, as well as their families, in their homes, schools and communities. Children and youth for purposes of this report are defined as being from birth to 21. Interagency collaboration seems to be a key to successful rehabilitation, transition, education and community inclusion. The majority of children who are injured will return to their regular classrooms and course of study. However, many will require support in order to do so. Of particular concern are those students who may exhibit late onset behaviors and learning difficulties which may not be recognized as a symptom of the brain injury by educators or families. Students with late onset problems may not have the supports that are needed.

Over the course of the past year, the Task Force reviewed service models, the current service delivery systems of care in Missouri for children, and identified gaps in those systems. The Task Force, then, made recommendations to the Missouri Head Injury Advisory Council which adopted this report. The recommendations relate to the following:

- 1) designating a lead state agency and service coordination system
- 2) coordinating and improving transition services
- 3) educating professionals who serve children
- 4) educating families on advocacy, and
- 5) expanding rehabilitation and community support services for children and youth and their families.

Many of these same concerns were addressed in an earlier report, *Pediatric Head Injury Recommendations for Improving the Service Delivery in Missouri*, issued in June 1994. At that time the council had made several recommendations to develop and provide the following:

- information to families at the time of hospitalization
- early notification to school districts

- information and training to educators
- information and training for families
- protocols for transitioning children from hospital or rehabilitation to the community
- access to service coordination

Some of these earlier recommendations have come to fruition and others will be addressed as the result of a recently funded three year grant from the U.S. Department of Health and Human Services to the Missouri Department of Health (awarded October 1997). Some of the progress since 1994 includes

- 4 development of an informational packet for families at the time of hospitalization (10,000 packets were produced in June 1997 by the Missouri Department of Health),
- 4 a designated case manager as a TBI resource in each regional and habilitation center for the developmentally disabled and in-service training for the designated case managers,
- 4 the addition of three more Department of Health service coordinators for individuals with traumatic head injuries, although they serve primarily adults,
- 4 holding regional workshops offering information on available community resources and services, and
- 4 applying for a federal grant which was awarded to the Missouri Department of Health, to improve and enhance the service delivery system, including early identification, family support and mentoring, training for case managers, and development of crisis intervention strategies.

The Task Force on Children and Youth included families, an individual with a traumatic brain injury, a neuropsychologist specializing in pediatrics, a state senator, a clinical nurse, and state agency staff administering Medicaid, special health care needs, education/special education, vocational rehabilitation, insurance, mental health and developmental disabilities programs. The Task Force members and others who assisted with this report are listed in the appendix. The Missouri Head Injury Advisory Council appreciates their time, energy and dedication to improve the system of care for children and youth with traumatic head injuries.

Recommendations for Meeting the Needs of Children and Youth with Traumatic Brain Injury

Part I. Overview

F.T.: A Case History

F.T. is a 15 year old boy who was injured at the age of 10. He sustained a severe traumatic brain injury from an amusement park accident. He was referred for a neuropsychological assessment by his school district because educators were unsure of how to manage his academic and behavioral problems. F.T. had recently entered the school district as a ninth grader, and he was failing all of his classes except for a D- in science and a B+ in physical education. He had particular problems with expression, following oral and written directions, and identifying the main idea in materials presented to him.

Teachers also were concerned about his short attention span, staring spells, and poor work completion. F.T. had received special educational services under a diagnosis of learning disabilities in his previous school district. This consisted of 1 hour per day of resource room assistance to help him organize his assignments and complete his homework. Since beginning in the new school, F.T.'s attendance has been adequate, and teachers perceived him as a friendly, outgoing young man. However, they were considering a secondary education diagnosis of behavior disorder because of the disruption caused by his impulsive and off-task behaviors.

At the time of his injury five years ago, he experienced full cardiopulmonary arrest at the scene of the accident and remained in a coma for three days. His initial Glasgow Coma Scale score was 6. A computerized tomography (CT) of the brain showed a large left tempoparietal contusion, but he had no other significant injuries. Upon transfer to acute rehabilitation 15 days post injury, F.T. displayed a dense right-side hemiparesis and could not talk, but he could follow simple one-step commands. During rehabilitation, he showed a rapid recovery of physical mobility, self-care skill, and basic language functioning. His attention span was extremely short, his short-term memory was poor, and he was impulsive and noncompliant in therapies.

Prior to injury, F.T. was a B-C student in school. He had never been retained or received special services; however, he had participated in a psychoeducational evaluation in the second grade because he was not getting his work done in class. Results indicated above-average intellectual functioning and average to above-average academic achievement. His mother revealed that F.T. had been physically and sexually abused for several months prior to injury, and she thought this might have contributed to his school problems.

A review of F.T.'s school and medical records indicated that he had participated in several cognitive assessments. At two months post injury, his overall intellectual functioning had recovered to the average range, though he displayed marked problems with sequential processing. In contrast, 4 years after his injury, F.T. demonstrated borderline intellectual functioning.

At the time of the current assessment (5 years post injury), F.T. underwent a single photon emission computerized tomography (SPECT) scan, which showed left temporal hypoperfusion. He again, displayed borderline intellectual abilities. Neuropsychological testing revealed significant psychological processing deficits, including moderate to severe impairments in the areas of verbal memory and learning, oral word fluency, attention, speed of processing, abstract reasoning, and problem solving. His cognitive strengths were his average to low-average visual memory and learning and his basic learning and academic skills. His sensorimotor skills were variable and generally in the average range, but his right hand was consistently slower and weaker than his left. These problems were considered consistent with his history of TBI and the SPECT results.

Behaviorally, F.T. was perceived somewhat differently by his teachers and parents. The teachers and his father reported clinically significant problems with attention/concentration, work production, and noncompliance. In addition to these problems, F.T.'s mother also indicated significant concerns about social withdrawal; aggressive behaviors (arguing, fighting, mood swings, temper tantrums); and delinquent behaviors (associating with bad companions, stealing, swearing, and truancy). On a behavioral self-report measure, F.T. identified mild, but not clinically significant, problems with daydreaming and arguing, suggesting a lack of insight and self-awareness.

Prior to discharge from the hospital unit, rehabilitation staff met with the mother and the director of special education from F.T.'s hometown. At this discharge planning meeting, they discussed F.T.'s current cognitive and behavioral problems and provided a brief overview of the expected course of his recovery and his educational needs. Unfortunately, the rehabilitation staff and the educator were unfamiliar with the new TBI category included in the revision of IDEA (Individuals with Disabilities Education Act). When he reentered school 6 weeks later, F.T. was classified as learning disabled and language impaired. Because of budget constraints, this small school district had been unable to hire a full-time speech/language therapist; instead, a speech/language therapist consulted weekly with the LD teacher to address F.T.'s language processing needs. At the end of the school year, the decision was made to retain F.T. in the fourth grade because he had missed so much school.

Frequent family moves made it difficult for educators to provide consistent programming for F.T. By the time he was referred five years post injury, his only educational diagnosis was learning disabled, with consideration

being given to an additional diagnosis of behavior disordered. Head injury was documented as a relevant factor under "Medical Concern."

F.T. certainly had multiple risk factors that could lead to a poor long-term outcome. He experienced a severe head injury with persistent cognitive and behavioral sequelae that interfered with his ability to keep up with same age peers, as indicated by neuropsychological testing and by the decline in his IQ scores over time. He had experienced academic problems prior to his TBI that were likely associated with his history of physical and sexual abuse. His home environment was chaotic, and litigation over the TBI fueled family conflict and divisiveness. His single mother had multiple stressors, including the injury of two of her children and severe financial problems, and she did not exhibit strong behavioral management or limit-setting skills. F.T.'s recovery from TBI was affected by frequent family moves and inconsistent (and sometimes inadequate) educational services due to educators' inexperience and limited educational resources.

On the positive side, F.T.'s mother cared for and advocated for him to the best of her ability. She was generally aware of changes related to the TBI and periodically sought improved services for him. F.T.'s legal settlement provided a source of income for such services, once the case was resolved. F.T. had strengths in visual and motor functioning, as well as the ability to regulate his angry outbursts and maintain a semblance of social relationships at school. The improved stability on the paternal side of the family provided another resource for F.T.'s social and emotional needs. Finally, school personnel acted as a safety net for F.T., recognizing the extent of his problems and requesting further input from professionals familiar with brain injury.

Clinical Recommendations

A systems model focusing on the child and his environment would suggest multiple points of intervention to be directed toward F.T. and members of his social environment. For example, F.T. might benefit from direct cognitive rehabilitation that included attention training and memory compensation strategies. He might also show a positive response to a behavioral program having a focus on (a) antecedent structuring of the environment (e.g., breaking large tasks into smaller steps, providing written directions that could be referenced to promote recall and task completion); (b) the use of videotaping to increase self-awareness and shape on-task behaviors, and (c) frequent positive reinforcement. An evaluation for pharmacological treatment of inattentive and impulsive behaviors would also be recommended.

General and special education teachers, the school counselor, the speech/language therapist, and the family should design goals that could be implemented in multiple settings by multiple treatment providers. Work behaviors need to be targeted as a prevocational objective. Given the extent of F.T.'s verbal processing deficits, social interactions should be closely monitored to ensure that he could establish and maintain adequate friendships. Finally, educators should draw on existing public policy to specify TBI as the appropriate educational diagnosis for F.T., thus eliminating unnecessary grade retention and increasing appropriate educational programming.

In addition, the resources of the family, health care specialists, and other community agencies should be mobilized. Stability in the family system would be essential for F.T.'s continued adaptation, so family therapy and parent training should be considered. Community agencies might be able to provide job training or respite care to the mother, to reduce her overall stress level. The problem of insufficient resources could be resolved based on interagency agreements across education, health, mental health, and social services providers. A pooling of resources is often necessary to address a child's needs following TBI, but there are not always mechanisms in place for this to happen. The state government where F.T. lives had funded five TBI service coordinators to identify interagency supports, but such services were not available in F.T.'s county. Supportive models of service delivery can be extended only if there is a public education and policy change. (Case history taken from Epilogue: An Ecological Systems Approach to Childhood Traumatic Brain Injury. In E.D. Bigler, E. Clark, J.E. Farmer (Eds.) Childhood Traumatic Brain Injury. Pro-ED: Austin, TX.)

Summary

F.T.'s course of treatment and rehabilitation is similar to many others who are hospitalized as the result of injury. For children who are hospitalized the focus is on physical recovery. Once a child is medically stable, the referring physician may refer the child for rehabilitation services such as speech/language, cognitive, physical, and/or occupational therapies. These therapies may be provided in an inpatient hospital/rehabilitation setting or on an outpatient basis. The type and duration of rehabilitation may be dependent on the insurance coverage for that service or ability to access other financial assistance and referral patterns. After they are considered medically stable and no longer require medical rehabilitation, they will return to school and to their homes. However, there may be times when homebound instruction is needed. Once their child is medically stabilized, parents are generally anxious for their child to return to home and to school.

With good transitional planning and communication between the hospital/rehabilitation staff and the school district the school should, at least, initially have information relating to the injury, deficits and strategies for assisting that child to learn. Sometimes, because the child may physically appear to have recovered from the injury, the child's deficits may not be readily apparent until he or she is faced with challenging situations. The child may then experience fatigue, problems with communication, and problem solving. For other children, problems may not be readily apparent until much later, when the child is facing increasingly more difficult learning situations. As the child matures and faces new challenges, difficulties in problem-solving, attention, memory concentration, and organization may become even more apparent. Often, the child may have problems with impulsivity and exhibit behavior problems, which may cause problems not only at school, but at home as well. The school may not have the expertise or resources to recognize what is happening with the child. The family may seek assistance from a community mental center, only to learn that their child is not eligible due to his or her diagnosis, or may seek services from a regional center for the developmentally disabled, which may also deny services.

Children with a mild or moderate traumatic brain injury do not generally receive either inpatient or outpatient rehabilitation (i.e. speech, occupational, physical and cognitive therapies). They are in the hospital for a short time and there may be little information that is obtained by the hospital regarding their potential deficits. Their cognitive and behavioral deficits may go unrecognized or be minimized. Parents or the hospital discharge staff may not notify the school district about the nature of the child's injury. It is, therefore, not unusual for a child to return to school and normal course of study only to experience problems with memory, attention, fatigue, and/or decreased impulse control.

When the child reaches junior and senior high, or if the student is that age when injured, vocational and independent living goals may need to be addressed. Older students with traumatic head injury may also have some other specialized needs such as peer support, substance abuse treatment, and driver's evaluation and training. Some of these services may be offered by rehabilitation programs.

Older students may opt to drop out of school as a way of dealing with their problems. Others who may have sufficient or close to the required credits for graduation may focus on graduation as the goal, and not on the vocational goals after graduation, which may need to be different than prior to their injury.

Traumatic brain or head injury is considered by educators as a low incidence disability. Most educators have not had training or experience in identifying behaviors associated with brain injury or in developing appropriate educational and vocational strategies to support students in the learning process.

For many students with brain injuries, their needs will be challenging to meet without coordinated, interdisciplinary planning involving all parties: the health care providers, the educators, the family and child, appropriate state agencies such as vocational rehabilitation, and the community. Case management or service coordination is an important component in order to achieve coordinated planning and care.

Part II. Service Delivery

Nationally, there have been efforts by several organizations and federal agencies to address needs of children and youth with traumatic brain injury. The Brain Injury Association (BIA) has convened a task force to study and

advocate for improved services. The BIA has produced a manual and other materials for educators and also has promoted prevention programs.

Emergency Medical Services for Children. There is a movement to establish sophisticated and designated trauma services specifically for children and to develop a system of coordinated services from hospital to home. The Emergency Medical Services for Children (EMSC), which is jointly administered by the Health Resources and Services Administration and the National Highway Traffic and Safety Administration, states that the majority of infants, children, and adolescents in the United States who might benefit from pediatric critical care services do not receive them.

The National Pediatric Trauma Registry at the Research and Training Center on Childhood Trauma and Rehabilitation (RTCCTR), funded by the National Institute on Disability and Rehabilitation Research, has determined that injured children who are unable to engage in age-appropriate activities are often discharged directly to their homes with no referrals for rehabilitation services, even though they have a clear need for rehabilitation therapies to help them regain their abilities in normal activities of daily living, such as communicating with others, dressing themselves, completing school assignments, and interacting with friends.

A study conducted at the RTCCTR found that children with similar functional impairments do not necessarily receive similar treatment following the acute phase of medical care. Specifically, patients treated at trauma centers that had onsite rehabilitation units were significantly more likely to have their rehabilitation needs addressed at discharge than patients treated at trauma centers without onsite rehabilitation programs. Many of these children in the later situation are not referred to rehabilitation and/or special education services.

A task force of physicians and health care professionals through Emergency Medical Services for Children (EMSC) has begun developing discharge guidelines that emergency and trauma care specialists can use to identify appropriate referrals of children between systems of care. The EMSC, National Resource Center, has issued an [Official Position Statement for Early Referral to Physical Medicine and Rehabilitation Services](#) recommending that every acute care facility make a formal and ongoing commitment to ensure that planning for rehabilitation services is included in every child's treatment program well in advance of the child's discharge from acute care.

Special Education. In 1990, Congress passed Public Law 101-476, Individuals with Disabilities Education Act (IDEA), which added traumatic brain injury as a separate category within the definition of disabilities and requires school districts to report the number of students with traumatic brain injuries. Although students with traumatic brain injuries, other health impairments and autism still account for less than 3 percent of all students with disabilities, these are the most rapidly growing categories according to the U.S. Department of Education, Office of Special Education Programs, as these reporting categories have just been more recently established.

IDEA also included the requirement for transition services to assist students with disabilities in transitioning from school to post school activities. Last year's reauthorization bill requires transitional planning at age 14. When the student is 16, the IEP is to reflect the needed services for transition.

U.S. Office of Special Education Program

The U.S. Office of Special Education Program has awarded federal projects to some state education departments and higher educational institutions to address (1) transitional services for individuals with traumatic brain injury; (2) pre-training, training, and master's level training for educators; and (3) models for inclusion. Most of these projects developed training models for educators and models for providing technical assistance to local school districts.

The Massachusetts Statewide Head Injury Program, with federal assistance, conducted a comprehensive follow-up study of people with traumatic brain injury who have transitioned from school into adult life. The results have been used to design an exemplary transitional services model for individuals who have transitioned from school into adult life, including materials for educators which is currently being printed.

Interagency Collaboration and System Delivery. On July 29, 1996, the President signed legislation, the TBI Act, authorizing \$24.5 million over the next three years to provide services for people with brain injury, prevent brain injuries and perform research. Funding was made available to assist states in improving the delivery and quality of service.

U.S. Health Resources and Services Administration, Maternal and Child Health Bureau. With funding from the TBI Act the Health Resources and Services Administration awarded grants to 21 states to enhance services delivery and capacity. Fourteen states received planning grants. Missouri is one of seven states to receive an implementation grant which will focus on family mentoring, training and certification for case managers, and crisis intervention strategies for children and adults. Three other states focus exclusively on children: Arizona, Alabama, and North Carolina. These projects will address training and interagency coordination.

State Education Models

Several state education departments have developed training for pre-service and inservice training to educators and offer technical assistance to local school districts. Since 1987, the Kansas State Board of Education, has funded a TBI Project administered by the University of Kansas Medical Center to provide training and technical assistance and consultation to educators and parents of students with TBI. Initially, a three year grant, the state extended the grant one more year, and has continued to fund the program. The state has since expanded the project to include other neurological disabilities (attention deficits and autism). As the result of federal funding from the U.S. Office of Special Education Program, the project was able to establish 19 TBI mini-teams throughout the state of Kansas. The 160 members of these mini-teams have received intensive training in TBI and are prepared to provide TBI inservice training and technical assistance and consultation to school personnel serving students with TBI in their geographical areas.

The state of New York awarded three grants for the development of model regional projects to help children with traumatic brain injury return to school and to address their ongoing education needs. In July 1994, based on the success of the three model programs, these programs were replicated statewide to include a total of nine regional TBI projects. A major function of these projects included the development of expertise within each region of the State so that, at the completion of the grant funding, school personnel would be better prepared to meet the needs of students with TBI and technical assistance, when needed, would be available. Support to families was an integral component of the services provided by the TBI projects.

The Rehabilitation, Research and Training Center on Community Integration of Individuals with TBI, Mount Sinai Medical Center, New York, New York, received funding from the New York State Education Department to develop a training curriculum, provide training and technical assistance to the New York City Public School educators. The workshops focus on overview of TBI, assessment strategies and instructional strategies. The RR&T Center also developed mini series for various school personnel such as for school counselors. The project supports a day and evening parent support groups that meet at Hunter College. Hunter College offers a two-semester, graduate-level certificate program for educators providing 18 credit hours on TBI, which make educators eligible for salary differential.

The Nebraska Department of Education funds Head Injury Kids Encounter (H.I.K.E.), a family support project. The H.I.K.E. program offers a weekend retreat designed for families. Activities are planned to meet specific concerns, such as the need for encouragement, friendships, transition planning, communication among family members, dealing with losses, spiritual issues, school concerns, sharing joys, and so forth.

In Missouri

Acute Rehabilitation and Transition Services

Pediatric Trauma/Rehabilitation. In Missouri, there are four trauma centers designated as pediatric trauma centers: University of Missouri Hospital & Clinics (both pediatric and adult trauma center), Columbia; Children's Mercy Hospital, Kansas City; St. Louis Children's Hospital and Cardinal Glennon Children's

Hospital, St. Louis. For children who are hospitalized their course of treatment and rehabilitation will be determined by the acute care hospital, and to a certain extent, by the family's insurance policy. Some hospitals and rehabilitation facilities have developed protocols for transitioning children from hospital to home and school. Once home, the availability of rehabilitation, education, and family supports will vary.

Kansas City

- Children's Mercy Hospital, Kansas City, has a dedicated 12-bed pediatric rehabilitation unit (inpatient). The medical director, who has provided inservice to trauma doctors about rehabilitation to ensure appropriate referral, is also the medical director to the Rehabilitation Institute, which has developed a post-acute rehabilitation program for both pediatrics (age 0 to 12) and adolescents (age 13 to 17 or 18, if still in school). The Rehabilitation Institute is developing a new program focusing on transitional adolescent services to link youth to vocational rehabilitation and other services needed to support them in the community.

The Rehabilitation Institute employs a Missouri certified teacher for second grade and higher and simulates classroom learning offering a full day, if feasible for the child, of occupational, physical, recreational, and speech/language therapies; and classroom activities. The educator works with the home school district to incorporate the child's educational curriculum into the program. When the child is discharged from the program, staff will go to the school, assess needs, and assist with developing the educational plan. The outpatient programs are funded by insurance, Medicaid, and the Bureau of Special Health Care Needs (Department of Health) for individual therapies.

The Rehabilitation Institute serves children and youth as far north as the Iowa border, south to the Arkansas border and just east of Columbia. However, staff report that they serve very few children from the immediate Kansas City metropolitan area (Kansas City School District). The staff educate families about future and anticipated problems and will provide follow up assistance as requested.

Columbia

- Rusk/HealthSouth, Columbia, has two main programs for children. One is an inpatient rehabilitation program that serves children from age 0 to 17. The program has a pediatric physiatrist and a pediatric team of allied health professionals who work with children and their families following the injury. Secondly, Rusk has outpatient programs for children offering physical, occupational and speech/language therapies.

In affiliation with Rusk/HealthSouth, faculty members of the University of Missouri Department of Physical Medicine and Rehabilitation provide outpatient medical and neuropsychological services. Staff often provide assessment and consultation services to school districts and other community-based service providers. The University is in the midst of exploring the use of telemedicine systems to support such work. The University provides training to post-doctorate fellows, interns and residents in pediatric head injury. The University is also provides support and training to state government through joint projects, such as the TBI grant awarded to the Missouri Department of Health.

St. Louis

- Cardinal Glennon Hospital has a designated inpatient seven bed unit with dedicated therapies for children with traumatic brain injuries. The unit, which has been in existence for seven years, serves children from age 2 to 16. For those children who are 16 or older the hospital refers them to a sister hospital, SSM, which not only provides therapies, but addresses other areas such as driving, sexual issues, and vocational needs.

Cardinal Glennon Hospital has three satellite outpatient sites located in Illinois, North St. Louis County and South County. Two physicians (developmental pediatrician and psychiatrist) conduct a follow up visit three months after discharge from the inpatient unit. Therapists will also generally follow up at three month intervals. The therapists invite schools to participate in discharge planning and sometimes will go

to the school to provide consultative services. A support group is offered through the Brain Injury Association.

Rehabilitation, Care and Community Support Services

An array of state services for children, in general, are provided and/or funded by four state agencies: Department of Social Services through Division of Medical Services (Medicaid), Division of Youth Services, Division of Family Services, and Division of Aging (nursing homes); Department of Elementary and Secondary Education through the Division of Special Education and Division of Vocational Rehabilitation; Department of Mental Health, through the Division of Mental Retardation and Developmental Disabilities, Division of Comprehensive Psychiatric Services, and Division of Alcohol and Drug Abuse; and Department of Health through the Division of Maternal, Child and Family Health, Bureau of Special Health Care Needs.

Most of these departments offer a case management or service coordination system as part of their programs. Some of these agencies contract or pay for a variety of services such as in-hospital care, therapies, respite, transportation, private duty nursing, nursing home care, and durable medical equipment based on financial need and/or diagnosis. As discussed later in this report, this array is not well coordinated nor blended to maximize the usefulness or appropriateness of services for children with traumatic brain injury. Eligibility criteria for these services may be based on financial need, diagnosis, medical necessity or a combination of these requirements. Some of the programs may be entitlement programs, such as Medicaid, others may be limited by the amount of funding appropriated to the program. For children with traumatic brain injuries the eligibility criteria for these programs may be conflicting.

Department of Social Services, Division of Medical Services

The state Medicaid program, administered by the Division of Medical Services, entitles eligible children to an array of services which may not be included in the state's plan for other beneficiaries. Known as the EPSD&T (Early and Periodic Screening, Diagnosis and Treatment) program or in Missouri, The Healthy Children and Youth Program, children are entitled to services prescribed as a result of a screen to be necessary to correct or ameliorate a defect or physical or mental condition. Services can range from office-based medical services to various mental health and developmental therapies in nontraditional settings, to home health and other long-term care services. The program covers children up to age 21.

Department of Health, Bureau of Special Health Care Needs

The Bureau of Special Health Care Needs was created to build systems of care that are family centered, community-based, and coordinated for individuals needing services beyond the normal and routine approach to health care delivery. The bureau administers the **Children with Special Health Care Needs Programs (formerly CCS)** which provides early identification and health services for participants birth to age 21. It may include diagnostic and treatment services involving medical care, hospitalization, and aftercare services to participants who require subspecialty preventative and primary care.

The bureau also provides service coordination for children eligible for the Medicaid EPSDT program, **The Healthy Children and Youth Program (HCY)**, who need primary and preventive care. The major components are: informing individuals about the HCY, referring for periodic screens, and service coordination for individuals to obtain services identified through screening.

The **Head Injury Program** provides coordinated services and assistance to individuals, primarily adults, who have sustained a traumatic brain injury. There are five coordinators who coordinate services to all but 41 counties throughout the state.

Department of Mental Health, Division of Mental Retardation and Developmental Disabilities

The Division of Mental Retardation and Developmental Disabilities offers a wide range of services to individuals with developmental disabilities, including individuals who receive a traumatic brain injury prior to

age 22, through contracts with local agencies, regional centers for developmental disabilities, and six habilitation centers which provide long-term residential care. The range of community-based services and supports for persons with developmental disabilities and their families include early childhood intervention, training, therapies, case management, and residential support.

The division administers the **Sarah Jian Lopez Medicaid Waiver** which allows parental income and resources to be disregarded for permanently and totally disabled children living at home who otherwise would require services at an institution. The Sarah Jian Lopez Waiver will allow up to 125 children, under age 18, with developmental disabilities to receive specialized care funded by Medicaid while continuing to live at home with their parents.

The division also administers the **Home and Community-Based Medicaid Waiver** to support eligible persons of all ages to live in the community whether in group homes, supported living, or with their families. Approximately 7,500 individuals are served by the waiver.

Another program, **Choices for Families**, provides funds to help meet the needs of family members with disabilities who live at home. Services include equipment, modification and supplies; evaluations; home and medical care; recreation and respite; therapies; transportation; and vocational services. Families can either pay for services and submit receipts for reimbursement, or obtain vouchers to purchase services.

The **Family Stipend and Loan Program** began in 1993 to assist families who have children under the age of 18 with developmental disabilities living at home. The programs help maintain and enhance families' ability to care for their children at home. The monthly cash stipend, which can amount to the maximum federal SSI payment for an individual with a disability who lives at home, can be used for goods and services to benefit the child. Low-interest loans, with a maximum amount of \$10,000 for a 60-month period, are also available for families who may not be able to get a loan through traditional means.

Elementary and Secondary Education

The 1990 Individuals with Disabilities Education Act (IDEA) included traumatic brain injury as a category of disability eligible for services. In order to receive special education services, however, students need to be referred. Parents, teachers, and physicians may refer a child for special education services. The Department of Elementary and Secondary Education has developed a state definition for traumatic brain injury and eligibility criteria for special education services.

Transitioning from School to Employment, Postsecondary Education. Children and youth with traumatic head injuries will experience many phases of transition throughout their lives, whether from hospital to school; elementary school to high school; or school to vocational training, higher education or work. The reauthorization of the Education for Handicapped Act, now referred to as IDEA, in 1990, also mandated transition services for students with disabilities and requires inclusion of a statement of needed transition services for students within the Individual Education Plan (IEP), beginning no later than age 16 and, when appropriate, beginning no later than age 14 or younger. These services are to assist the student in transitioning from school to post school activities.

Division of Special Education

The Missouri Department of Elementary and Secondary Education, Division of Special Education ensures that all students with disabilities between the ages of three and twenty-one years as prescribed by Missouri statutes have a right to a free appropriate public education (FAPE). The department has defined special education as specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings and instruction in physical education. The term includes speech pathology, or any other related services, if the service consists of specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, and is considered special education rather than a related service under state standards. The term

also includes vocational education, if it consists of specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability.

Related services are defined as transportation and such developmental corrective, and other supportive services as are required to assist a child with a disability to benefit from special education, and includes speech pathology and audiology, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, early identification and assessment of disabilities in children, counseling services, including rehabilitation counseling, and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in schools, and parent counseling and training. Medicaid will fund medically necessary physical therapy, occupational therapy, speech pathology, psychological and transportation services called for in the IEP (Individual Education Plan).

In 1991, the Missouri Department of Elementary and Secondary Education appointed an advisory committee to develop a state definition for traumatic brain injury and a set of eligibility criteria for special education services. The Division of Special Education produced a manual, *Developing Individual Education Plans for Students Who Have Suffered Traumatic Head Injury: Procedural Guidelines*, to be used along with the guide, *The Educator's Manual*, produced by the then, National Head Injury Foundation (now known as the Brain Injury Association). The division is in the process of updating this guide.

In 1996, the Department of Elementary and Secondary Education received a 5- year grant to provide statewide systematic approach to providing transition services to assist youth with disabilities. The grant is funding the Missouri Transition Alliance Partnership (MOTAP) Project that supports one system for the transition of students with disabilities from school to adult life. The project is currently funding three regional grants to coordinate and promote transition within certain geographic areas. The goal is to have similar projects throughout the state. The project is a joint effort with the Division of Vocational Rehabilitation. MOTAP also interfaces with Missouri's Community Careers System (School to Work Initiative) to develop one system that services all students as they transition from school to work. MOTAP also supports training and information dissemination in cooperation with MPACT (Missouri Parents Act) and Center for Innovations in Special Education (CISE).

Division of Vocational Rehabilitation

The Department of Elementary and Secondary Education administers a wide range of services to help individuals with disabilities become employable. The program is supported by federal and state funds. To be eligible an individual would need to have a mental or physical disability which creates an impediment to employment and would benefit from rehabilitation services. There is no age limitation. The division operated offices throughout the state and in each office a counselor has been assigned to work with individuals with traumatic head injuries.

Some of the services vocational rehabilitation provides includes:

- assessment to determine the extent of disability and what services are required for the individual to become employed
- evaluation to determine the kind of work for which a client is best suited
- guidance in choosing suitable employment
- individual counseling during the rehabilitation process
- assistive devices
- assistance in finding a job

The division also administers some funding to independent living centers and for the personal care assistance program. The independent living centers provide four core functions for individuals with disabilities, regardless of age: 1) advocacy, 2) independent living skills & training, 3) peer support, and 4) information and referral.

Assistive Technology

Assistive technology services, including evaluation and purchase of devices, may be available through Medicaid, if medically necessary; education; Bureau of Special Health Care Needs; Division of Vocational Rehabilitation; and the Division of Mental Retardation and Developmental Disabilities. As with other services, in order to obtain assistive devices through these agencies, children and youth with traumatic brain injuries would need to meet the eligibility criteria of those agencies.

Missouri Assistive Technology Project

The Missouri Assistive Technology Project is administered by the Governor's Council on Disabilities, Department of Labor and Industrial Relations, with funding from the National Institute of Disability and Rehabilitation Research, U.S. Department of Education in compliance with the Technology-Related Assistance for Individuals with Disabilities Act, P.L. 100-407. The primary mission of the project is to develop a comprehensive assistive technology service delivery system that will be responsive to consumers of all ages with all types of disabilities.

The project accomplishes its mission through information dissemination, public awareness, information and referral services, equipment demonstration and training and advocacy for policies and funding to support access to assistive technology. The Missouri Assistive Technology Advisory Council is the coordinating mechanism for the delivery of assistive technology devices and services.

Interagency Planning and Policy Coordination

The Missouri Head Injury Advisory Council was created to plan for a service delivery system for individuals with traumatic head injuries and their families. The council has advocated and has been successful at obtaining legislation and funding to (1) establish a head and spinal cord injury registry, (2) establish a statewide trauma system; (3) establish the Department of Health as the lead service agency for head injury; (3) expand Medicaid services to include post-acute rehabilitation, primarily for adults; and (5) obtain service coordination and other community services. The council supported legislation which expanded the definition and eligibility for Division of Mental Retardation and Developmental Disabilities services to include persons with traumatic head injury who are injured prior to age 22.

The Missouri Planning Council for Developmental Disabilities was established by federal and state law to plan and coordinate service delivery for individuals with developmental disabilities. The council carries this mandate out through eleven regional councils, also established by state law, to plan for local service delivery. The Missouri Planning Council has undertaken a number of projects, many of which have been expanded to include individuals with traumatic head injuries and their families, including Partners in Policymaking, Parent-to-Parent Conference, Show Me Choices, and Home of Your Own.

The Governor's Council on Disability, housed in the Department of Labor and Industrial Relations, advises state agencies on policies and practices which impact people with disabilities to encourage system changes to eliminate barriers to people with disabilities, promotes employment of people with disabilities, and over see state compliance with the Americans with Disabilities Act.

Lead State Service Agency/Service Coordination

The Missouri General Assembly, in 1991, passed legislation designating the Department of Health as the lead agency for individuals with traumatic head injury. The legislation established the Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services in the department. In 1995, the department, by way of an Executive Order, abolished the division and assigned that responsibility to the Division of Maternal, Child and

Family Health, Bureau of Special Health Care Needs. The program either employs directly or contracts staff for service coordination which coordinates services primarily for adults, as the Bureau of Special Health Care Needs also employs service coordinators for children with special health care needs, which may include children with traumatic brain injuries.

In-Service Training

The Missouri Division of Special Education contracts with the Center for Innovations in Special Education (CISE), University of Missouri-Columbia, for continuing education training, information and dissemination activities, and resource materials to support educators in assisting students with disabilities. CISE sponsors and coordinates two annual conferences, publishes a quarterly newsletter, provides graduate instruction, and operates a resource library and material loaner program (manuals, videotapes, and books). CISE has purchased materials on traumatic brain injury for educators as part of its loaner program and invites the Missouri Head Injury Advisory Council to display materials at its conferences. The Division of Special Education with assistance from CISE is updating and publishing a manual for educators. CISE has also hired staff to provide training on transitioning students from school to work/career.

The Missouri Head Injury Advisory Council has sponsored an annual statewide conference since 1986, and has also either sponsored or cosponsored regional workshops and other statewide workshops on head injury. The council routinely exhibits at the health educators conferences and the young years conference sponsored by the Department of Elementary and Secondary Education.

The Department of Health with funding from the three year TBI grant is developing a training academy and certification program for case managers/service coordinators from the various state agencies which may serve individuals with traumatic head injury. The grant also calls for in-service for advocacy organizations such as Missouri Protection and Advocacy Services and MPACT (Missouri Parents Act).

Advocacy Training for Families. MPACT, Missouri Parents Act, is a statewide Parent Training and Information Center for parents of children with disabilities. The program receives funding from the U.S. Department of Education and the Missouri Department of Elementary and Secondary Education for the purpose of providing parents with information and support enabling them to secure appropriate education and services for their children. The program also receives funding from the Missouri Department of Elementary and Secondary Education. MPACT provides parent-to-parent training, information and referral, a resource library of books and tapes, newsletters and individual assistance with special education issues. The organization has offered to train parents of children with traumatic head injuries and has conducted workshops during the Missouri Head Injury Advisory Council conference and regional workshops.

The Brain Injury Association of Missouri was formed as a family support and advocacy organization. The BIA has a network of support groups around the state and is working with the Department of Health and the Missouri Head Injury Advisory Council to develop and implement a family mentoring program.

Independent living centers are located throughout the state and are required to provide four core services: independent living skills training, peer support, advocacy, and referral to individuals with disabilities, including children and youth with traumatic brain injuries.

Part III. Service Gaps

Acute In-patient Care and Rehabilitation. Much concern has been expressed regarding the changes in health care delivery and the impact on rehabilitation. The changes are reflective, in part, of efforts to reduce health care costs by those who bear the costs. Some of the changes have been attributed to managed care organizations which focus on short term outcomes and which have changed the delivery of care through their case

management/gatekeeping systems. As with private health care insurance programs, state agencies administering health and long-term care programs are also looking to a managed care approach.

Rehabilitation programs are also undergoing changes in response to managed care. Some programs are phasing out of facility based rehabilitation and providing rehabilitation in the home setting. Most, regardless of setting, are focusing on short term outcomes in response to managed care

This means that much of the acute hospital care is focused on stabilizing children medically so that they can be discharged to their homes. To receive rehabilitative services they will generally need to be referred by their physicians. For children who are not eligible for Medicaid, yet have been denied rehabilitation coverage by their insurance company, there are few options for rehabilitation, including behavior, cognitive therapies and substance abuse treatment following hospitalization. If the therapies are regarded as medically necessary, then the school districts are not responsible for providing these services. If they are viewed as educationally relevant and are included in the child's individual education plan, then the school district would be responsible.

While hospital and/or rehabilitation staff may provide good transition services to assist children with school/community reentry, that transition plan relates to the short term. For many children their behavior and cognitive deficits may not surface until they face more complex situations or tasks. These problems may not only create problems in the educational setting, but at home and in the community as well. Some rehabilitation programs will provide consultation services to school districts when requested. But, in general, there is not a systematic approach for tracking children with traumatic brain injuries over time in order to assess and provide supports as needed.

Family Support/Community Integration. There are other types of services that children and their families may need, including respite, home modifications, in-home support, counseling, substance abuse rehabilitation, peer support, and vocational training. Children and youth with traumatic brain injuries are often not eligible or able to access some of these services from state agencies due to (1) their diagnosis, (2) the state agency may not contract with providers who specialize in traumatic brain injury, or (3) the state agency may not pay for the particular service needed such a neuropsychological evaluation or cognitive rehabilitation.

Lead Agency/Interagency Agreements. Children and youth with traumatic head injuries and their families generally interact with large complex, yet very different systems: medical/rehabilitation, education, financial (insurance, social security, Medicaid), and state agencies (Department of Health, Department of Mental Health, Division of Vocational Rehabilitation). Care provided may differ from child to child, not only due to the nature and extent of injury, but also differences in resources available. Families often find it difficult to navigate the complexities of these service systems. These systems may not have experience and expertise in traumatic head injury rehabilitation and care.

While the Department of Health is designated as the lead state agency for head injury services, the department does not have a comprehensive system for early identification, information and referral, and service coordination for children with traumatic head injuries. Children with traumatic head injuries may be eligible for service coordination and other services through the Bureau of Special Health Care Needs. The special health care needs service coordinators do not specialize in a particular disability, as they serve children with disabling and chronic health care needs. The special health care needs service coordinators, as well as the case managers from the regional centers for the developmentally disabled, need to have training and expertise in traumatic brain injury to understand the problems and associated needs in order to assist children and their families throughout the process—transitioning from hospital to home to school to vocational training to higher learning to community living.

Continuing Education and Professional Development. Community service providers for persons with disabilities are generally not trained as to best serve young people with brain injury. Families may seek services from various systems designed for individuals with disabilities, but may find that those systems may not understand the deficits associated with traumatic brain injury.

Most teacher training programs do not include information on traumatic head injury, resulting deficits, assessment, and teaching strategies. As most children will be placed in the regular classroom, educators, as well as special educators, need to know this information. For children who present special problems for educators they often will look for experts in pediatric head injury to assist with evaluation and developing appropriate teaching strategies. Educators need access to materials, training, and possible consultants or other resources. Both pre-service and inservice training programs need to be developed and available.

Family Training and Advocacy. After an injury suddenly occurs, families may find themselves in a different role of care taking and advocacy, which they may initially be unprepared to fill. They also may not be prepared to be active participants in the decision making for their child, and providers may not acknowledge family members in this role. As the child grows and needs change, families may find that their advocacy needs change as well. Families and individuals with traumatic head injuries are generally involved with many different complex systems over time: medical, rehabilitation, education, insurance, vocational rehabilitation, and social security. Since the family is often the advocate and sometimes the service coordinator, families need information on head injury, services available, and how to access and advocate for those services. Those organizations which provide parent training or offer advocacy services to children with other disabilities need to have an understanding of the issues and needs of children and youth, as well as their families, with traumatic head injuries.

System Delivery Planning and Policy. While the Missouri Head Injury Advisory Council was created by law to plan for services for persons with traumatic head injury, there are other advisory and planning entities which assist with this goal of planning and interagency coordination for children with disabilities. For example, P.L. 94-142 Panel plans for special educational needs of students, including those with TBI. There is also the Statewide Independent Living Council, Governor's Council on Disability, Missouri Planning Council for Developmental Disabilities, Missouri Assistive Technology Advisory Council, and the Missouri Transitional Alliance Partnership State Advisory Council.

The MC+ Quality Assurance and Improvement Committee, established by the Department of Social Services, monitors care provided under the Medicaid managed care plans. There needs to be ongoing coordination between MC+ and Medicaid fee-for-service programs so that children under MC+ (managed care) who are injured and, once determined as permanently and totally disabled (PTD), and no longer covered by MC+, will transition smoothly to those services which are covered under the fee-for-services program.

Part IV. Recommendations

I. Designate Lead Agency/Interagency Agreements

- Designate the Department of Health, Division of Maternal and Child Health, Bureau of Special Health Care Needs as the recognized lead agency responsible for the coordination of services and develop interagency agreements to ensure coordination and cooperation in the delivery of services for children with traumatic head injuries. The Bureau of Special Health Care Needs would be responsible for
 - Developing interagency agreements with other state agencies, hospitals, and schools with the assistance of the Missouri Head Injury Advisory Council
 - Designating and assigning Bureau of Special Health Care Needs service coordinators to serve children with traumatic head injuries so that they can develop the expertise and experience necessary to adequately serve these children and youth
 - Providing information and referral services.
 - Assisting in the identification of children with traumatic head injuries in order to plan for services which may be needed in the state.

II. Continuing Education and Professional Development

Consumer/Family Training and Advocacy

- Develop competencies, curriculum and training to support advocacy by parents and self advocacy by survivors.

In-service Training/Professional Development

- Develop competencies, curriculum and training for educators, regarding assessment, IEP development, teaching strategies, transitional planning, and behavior interventions.
- Develop competencies, curriculum and training for casemanagers, and other professionals, including Division of Youth Services staff, Bureau of Special Health Care Needs service coordinators, Missouri Juvenile Justice Association, Division of Family Services, and Regional Centers for the Developmentally Disabled case managers.
- Develop competencies, curriculum and training for pre-service training for educators.

III. Acute In-patient Care and Rehabilitation

- The Task Force recommends that the council study the affects that managed care is having on the delivery of acute and rehabilitation care and make appropriate recommendations to those who set policy for the insurance industry, state Medicaid program and other pertinent state programs.
- Advise the Department of Social Services, Division of Medical Services to coordinate the managed care and fee-for-service programs for children under MC+ who become eligible for Medicaid fee-for-services as the result of PTD (permanently and totally disabled) eligibility.
- Recommend to the Department of Social Services that state contracts for Medicaid managed care plans include provisions for requiring managed care organizations to have arrangements or agreements with state and local social services, public health, vocational rehabilitation and mental health agencies in order to coordinate services with those agencies.

IV. Community Based Rehabilitation (outpatient therapies)

- The Task Force recommends that a council committee study and recommend how rehabilitation, habilitation and educational services can be adequately supported with blended funding.

V. Transition Planning

- Develop a protocol to support the transition of children from hospital/rehabilitation to home/school.
- Recommend to the Department of Health that case managers/service coordinators be designated to assist families and children and youth with traumatic head injuries in transitioning from hospital to home/school.
- The Task Force recommends that a committee or task force be designated to bring specific recommendations for supporting young adults with TBI who have dropped out of school.

VI. Family Support/Community Integration

- Develop interagency agreements between the Department of Mental Health; Department of Social Services, Division of Medical Services, and Department of Health, Division of Maternal, Child and Family Health as to how those services which are provided to individuals with other disabilities may be enhanced to be appropriate to the needs of children and youth with traumatic head injuries. These services

include respite, counseling, behavior management, ongoing evaluation, substance abuse treatment, and peer counseling.

- Advocate for additional state funding for those services not otherwise available through existing agencies and programs to support families and children in the community.
- Provide transitional services to children and youth who are receiving services under the Medicaid Early and Periodic Screening, Diagnosis, and Treatment program (the Healthy Children and Youth Program) as they approach the age of 21, which is the cut off age for that program.

VII. Consultative Services

- Develop regionalized consultive services for schools to access to assist in the planning and implementation of special education services for students with TBI.
- Develop and implement crisis intervention services and strategies.

VIII. Long-Term Care

- Develop and adopt program models to support children in the home and options for those who need more structured care in lieu of inappropriate placement into nursing homes.

IX. Service Delivery Planning and Policy

- Assure continued representation on appropriate councils which advocate for children such as the Missouri Planning Council for Developmental Disabilities, Special Education Advisory Panel, Governor's Council on Disabilities, Statewide Independent Living Council, etc.

X. Prevention

- Provide continued support for traffic safety legislation, the recommendations made by the council Task Force on Playground Safety, and other issues identified by the council Prevention Committee.

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